

Transition between child and adult services for young people with ADHD: findings from a British national surveillance study

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Abstract

Background: Optimal transition involves continuity, joint care, planning meetings and information transfer. To plan services, commissioners and service providers need data on how many people require that service. Although Attention-Deficit/Hyperactivity Disorder (ADHD) frequently persists into adulthood, evidence is limited on transitions between child and adult services.

Aims: To estimate the national incidence of young people taking medication for ADHD that require and complete transition, and describe the proportion that experienced optimal transition.

Methods: Surveillance over twelve months using the British Paediatric Surveillance Unit and the Child and Adolescent Psychiatry Surveillance System, including baseline notification and follow up questionnaires.

Results: Questionnaire response was 79% at baseline and 82% at follow up. For cases aged 17-19, incident rate (range adjusted for non-response) of transition *need* was 202-511 per 100,000 people aged 17-19 per year, with *successful* transition of 38-96 per 100,000 people aged 17-19 per year. Cases were mostly male (77%) with a comorbid condition (62%). Half were referred to specialist adult ADHD and 25% to general adult mental health services; 64% had referral accepted but only 22% attended a first appointment. Only 6% met optimal transition criteria.

Conclusions: As inclusion criteria required eligible cases to be on medication, these estimates will represent the lower limit of the need for transition. Two critical points were apparent; referral acceptance and first appointment attendance. The low rate of successful transition and limited guideline adherence indicates significant need for commissioners and service providers to improve service transition experiences.

Key Words: Attention-Deficit/Hyperactivity Disorder, Surveillance, BPSU, CAPSS, Incidence

1 **Introduction**

2 In order to plan services, commissioners and service providers need accurate and timely data on how
3 many people may require that service. There are currently limited national and international data on
4 the number of young people with Attention-Deficit/Hyperactivity Disorder (ADHD) who need
5 transition to adult services when they become too old for child services. ADHD affects approximately
6 5% of the childhood population, 15% of whom still meet the full, formal diagnostic criteria at age 25;
7 up to 65% still have impairing symptoms at age 25 but may not meet the full formal criteria (1, 2).
8 Consequently, there is a group of young people in need of continued support for the management of
9 ADHD in early adulthood. There are few empirical data on the number of young people with ADHD
10 who wish to access ongoing care in adulthood, or the number that successfully do so. Some studies
11 have attempted to quantify national estimates for transition, but have either focussed on all
12 neurodevelopmental conditions rather than just ADHD, or were limited geographically (3, 4).

13 The current study aimed to estimate the incidence of young people with ADHD who need transition
14 from child and adolescent services to adult services across the United Kingdom (UK) and Republic of
15 Ireland (ROI) (henceforth, the British Isles). For the purposes of this study, transition refers to the
16 transfer of care from Child and Adolescent Mental Health Services (CAMHS) or Paediatric services to
17 an adult service for continued treatment for ADHD, once the young person reaches the service
18 transition boundary. The main objectives of the study were; to describe the group of young people
19 diagnosed with ADHD and requiring medication beyond the end of children's services in terms of range
20 and mean age for transition; to estimate the incidence rate of young people with ADHD who require
21 ongoing medication for ADHD after they pass the age-boundary for the child service; to estimate the
22 proportion of young people with ADHD judged in need of transition to Adult Mental Health Services
23 due to ongoing need for medication that successfully transferred to a specialist health service; and to
24 describe the proportion of young people who experience optimal transition. Successful transition was
25 defined as a referral to an adult service made, accepted and the first appointment attended, and

optimal transition as joint care, planning meetings, information transfer and continuity of care (5), and in line with recommendations in the current NICE guidelines for ADHD (6).

Methods

This study, which was part of a research programme that explored transition in ADHD (CATCh-uS) funded by the National Institute for Health Research (HS&DR 14/21/52) (7), used the British Paediatric Surveillance Unit (BPSU) and the Child and Adolescent Psychiatry Surveillance System (CAPSS) to collect prospective data on the number of young people with ADHD who undergo transition from children's services to adult mental health services. These surveillance units provide a method that allows the collection of reliable national estimates of service level incidence about rare health conditions or events in paediatrics and child mental health services to improve their identification and clinical management. The surveillance methodology is described in more detail elsewhere but is briefly summarised below (8-11).

Young people taking medication for a clinical diagnosis of ADHD requiring transition to an adult service for continued treatment, were notified prospectively using the BPSU and CAPSS methodology over thirteen months from 1st November 2015 to 30th November 2016. The first (pilot) month was discarded as per BPSU and CAPSS protocol. Consultant Paediatricians and Consultant Child and Adolescent Psychiatrists in the British Isles were systematically prompted using a monthly email or postal reporting card, which asked them to indicate the number of eligible cases they had seen in the previous month, or 'nothing to report'. Details regarding each reported case were subsequently gathered by study investigators using a notification questionnaire sent to the reporting clinician. Information on the outcome of the transition of eligible cases were collected using a follow up questionnaire nine months after notification. Baseline notification and follow up questionnaires were developed using the BPSU and CAPSS templates, which comprised structured questions (30 at baseline, and 19 at follow up) with two open text responses. A copy of the questionnaires used can be

found as supplementary material. Only cases confirmed as eligible at baseline were sent a follow up questionnaire nine months later. Duplicate reporting of cases was checked by matching minimal identifiers.

The study was approved by both BPSU and CAPSS Executive Committees. Health Research Authority (HRA) and Confidentiality Advisory Group (CAG) approvals permitted access to case note information without patient/parent consent (IRAS registration number: 159209, REC reference: 15/YH/0426, CAG reference: 15/CAG/0184).

Case definition criteria for notification

The case definition criteria were developed to be itemised and precise, and to specify the need for the young person to need ongoing support for medical treatment from specialist adult mental health services, as outlined in the NICE guidelines (6). It was designed in close collaboration with both BPSU and CAPSS to ensure that both Paediatricians and Child and Adolescent Psychiatrists would identify young people in a similar manner. The surveillance asked for young people seen in the previous month to be reported, if they were judged to meet the following criteria by the reporting clinician;

- Clinical diagnosis of ADHD, under the care of Child and Adolescent Mental Health Services (CAMHS) or Paediatrics reviewed within six months of the service's upper age (transition) boundary.
- Considered to require and willing to take continued medical treatment for symptoms of ADHD after crossing the transition boundary of the child service.
- Comorbid diagnoses, including learning / developmental disabilities, were included only if it was the ADHD that required ongoing medical treatment in adulthood.

Data analysis

Analysis of data was descriptive. Response rates at each stage of the study are described, as are sociodemographic details of the reported cases. An incidence rate is defined as the number of new health related events, in a defined population, during a stated period of time (12). The incidence rate of transition was calculated by dividing the number of confirmed young people with ADHD who need transition identified over the course of the study's twelve month surveillance period, by the population at risk. The population at risk was derived by applying the estimated prevalence of ADHD (approximately 5% in the child and adolescent population) (1) to the total number of children aged 17-19 years in the British Isles as reported in 2016 (n=2,333,035) (13). The quotient was then multiplied by 100,000 to provide the incidence rate of transition per 100,000 population of people aged 17-19 per year. Two incidence rates were calculated; the incidence of young people who required transition as defined by the case definition criteria, and the incidence rate of successful transition in the obtained sample, defined as those whose referrals were accepted and attended their first appointment in the adult service. The observed incidence rate was adjusted to take into account the age of the young person, the current NICE guidance about the age of transition (18 years) and missing data (failures to notify or return questionnaires) as suggested in a previous study – see Table 2 (14).

Results

Table 1 illustrates the return of questionnaires for each stage of the surveillance study. The mean monthly response rate was 94% in BPSU and 53% in CAPSS. A total of 614 cases were reported by 249 different clinicians. The overall response rate to the baseline questionnaire was 90% from BPSU and 67% from CAPSS clinicians, and at follow up was 84% and 80% respectively. The response rates include contacts with clinicians who provided an explanation for not returning the questionnaire, including for reasons such as inability to recall the patient reported, reporting the case in error, or subsequent realisation that the case did not meet the definition criteria.

No cases were reported through both BPSU and CAPSS. Thirteen duplicate reports were identified from clinicians who reported the same case more than once during the surveillance period. Seventeen questionnaires could not be completed at follow up as the clinician no longer had access to the patient's records, or was no longer in post. Some questionnaires at baseline and follow up were returned blank or not fully completed (n=86). However, information from partially completed questionnaires was included in the analysis. The 315 eligible cases were reported by 148 different clinicians.

>> insert Table 1 <<

Demographics of young people reported

The population of young people reported was largely male (77%) and White British (91%). Cases were reported from across the British Isles but most (over 85%) were seen in England. The modal age boundary between child and adult services was 18 years old, but ranged from 14 to 19 years. Two cases who did not originate from the British Isles, were international students seen in private practice in England. The reported age range of reported cases extended from 14 to 20 years, although 85% were aged 17 to 19 years at the point of referral for transition, and age was not reported for 6% of cases.

A large proportion of cases (56% from paediatricians, 68% from psychiatrists) were reported to have a comorbid condition; for 25% the comorbidity was an autism spectrum disorder (ASD). Polypharmacy was common; 23% of cases from paediatricians and 41% from psychiatrists were prescribed more than one medication.

Incidence of transition

Table 2 demonstrates the incidence calculations, adjusted for age and non-response. In total, there were 315 confirmed eligible cases (202 BPSU, 113 CAPSS). Follow up questionnaires were received for 247 cases; 55 cases (22 BPSU, 33 CAPSS) confirmed that a successful transition was achieved (i.e. a referral made, accepted, and the young person attended first appointment in the adult service). When only the cases aged 17 to 19 years were extracted from these data, there remained 269 eligible for transition, and 51 that were reported to have had a successful transition.

Figures in bold in Table 2 estimate the range for eligible and successful transition. The Adjusted Incidence Rates provide a likely range within which the actual rate is likely to fall, and suggest between 202.9 and 511.2 per 100,000 17-19 year olds per year were eligible but successful transition was less common (38.5 and 96.9 per 100,000 young people aged 17-19 years per year).

>> insert Table 2 <<

Transition quality and outcomes

Half of all the reported cases, regardless of age at referral, were referred to a specialist adult ADHD service, just over a quarter to general adult mental health services, and 10% were referred back to primary care. Referral destinations were similar regardless of whether the young person was reported by a paediatrician or a psychiatrist.

In total, 64% (n=158) of the 247 cases who were referred to adult mental health services were accepted (BPSU 52%, CAPSS 86%), but only 22% (n=55) were reported to have attended a first appointment (14% BPSU, 38% CAPSS) – Figure 1. Reported reasons for failed transitions included; the patient disengaged and no longer wanted to take medication (n=3), the referral did not meet adult service criteria (n=1), there was no funding available (n=1), or the adult service was closed to new

referrals due to lack of resources or long waiting lists (n=4). No reason for a failed transition was given for the remaining cases (n=46).

>> insert Figure 1 <<

Nearly all (93%) clinicians reported that the young person had been involved in the planning of the transition process, and over 80% reported that the parent or carer was also involved. More Child and Adolescent Psychiatrists than Paediatricians reported access to (81% vs 39%) and use of (66% vs 36%) a transition protocol in their organisation.

At baseline notification, only 6% of paediatricians and 10% of psychiatrists indicated that all five optimal criteria pre-transition (see Table 3) were apparent in the transition planning. At follow up only 2% of paediatricians and 6% of psychiatrists considered that all nine optimal criteria post-transition had been adhered to. Some elements were reported considerably less frequently at follow up than at baseline, which suggests that clinicians anticipate being able to complete these elements, but when providing a retrospective report at follow up some elements may either not have been recalled or not have been carried out. These included: information sharing (84.6% at baseline vs. 68.8% at follow up), young person involvement (81.4% vs. 69.6%) and joint working (25.5% vs. 10.5%).

>> insert Table 3 <<

Discussion

This surveillance study generated the first national data to estimate the number of young people with ADHD taking medication who require and complete a transition to an adult service in the British Isles.

Our findings suggest that the annual scale of the need for young adults with ADHD who require transition to adult services for ongoing medication in the British Isles lies between 202.9 and 511.2 per 100,000 17-19 year olds per year. Given the study's inclusion criterion that the eligible young person had to need and want to continue with medication for ADHD after reaching the age boundary of the children's service, which does not take into account the demand for psychological support, these figures are likely to be a considerable underestimate of the actual need for service provision. Further, a comparison of the surveillance data collected in the current study with the Clinical Records Interactive Search (CRIS) at the South London and Maudsley NHS Trust (SLaM) highlighted that surveillance using CAPSS only identified 25% of potential ADHD transition cases in the London area (11). Sadly, there were no comparable data to triangulate with BPSU reports, but the CRIS data emphasise that although our estimates should therefore be treated as extremely conservative, they remain the best empirically-based British Isles data available for service commissioners and providers. The use of population data restricted to age 17-19 is a limitation of the study, and may have therefore excluded relevant cases, however it reflects 85% of eligible reported cases and the NICE guidance that transition should occur by age 18. The requirement that reported cases needed ongoing medication aimed to increase reliability in reporting eligible cases by having an unequivocal reference for the reporting clinician.

Previous studies have only been able to estimate the number of transition cases in smaller localities that are difficult to compare directly with our findings. A London-based study suggested an average of 12 neurodevelopmental cases per CAMHS team annually that require a transition to an adult service, with 8 of the 12 making the transition successfully (3). A study from the Republic of Ireland used the same methodology and found 20 ADHD cases from 4 CAMHS teams annually requiring transition, with only 3 successfully transitioning to an adult service (4). Similarly there are a lack of comparative international data on transition in ADHD; an ongoing European study on transition focusses on mental health transition generally but is not specific to ADHD (15). Given the rise in prescriptions for ADHD over the last couple of decades (16), estimates may quickly become out of

date as later cohorts are likely to contain a higher proportion of young adults who may have benefitted from medication and therefore wish to continue to take it. A recent report reviewing children and young people's mental health care highlighted a lack of data availability and monitoring of transition (17), and further, reviews such as this only consider young people up to the age of 18 so knowledge of the needs of young adults in their later teens or early twenties is poor.

The estimated annual incidence of successful transitions lies between 38.5 and 96.9 per 100,000 young people aged 17-19 years per year, which suggests that only a fifth of those requiring transition for ongoing medication successfully made the transfer. A small proportion of failed transitions related to the young person disengaging from services or their medication, which would render them ineligible by our definition, but it may also relate to the lack of suitable services for onward referral. A study of a locality in North West England reported that only 15% of patients eligible for transition actually successfully transferred to the adult service (18). Others have demonstrated above predicted levels of medication cessation between the ages of 15 to 18, prior to transition, which may be influenced by the lack of availability of services (19). Data from UK primary care suggested that only 18% were still taking medication for ADHD at age 18 (16). These findings suggest a worrying discontinuity of service between child and adult services, given that patient registry studies of young adults who discontinue their medication show poorer outcomes compared to those who continue to take it (20). Given the number of young people reported in this surveillance study that did not attend the first appointment in the adult service, it is possible that the transition referral for ongoing treatment might reflect a clinician decision regarding the need for treatment, rather than a decision made by the young person.

Our findings suggest poor adherence to the recommendations for transition from the National Institute for Health and Care Excellence (NICE) guidelines for ADHD. NICE recommend that a good transition between child and adult services should be complete by age 18, involve a detailed care plan, include a formal joint meeting between the child and adult service, use the care programme approach,

and involve the young person and the parent or carer (6). The guidelines do not specify what type of adult service a young person should be transitioned to, only stating adult mental health services, and encouragingly over 75% of cases in this study were referred to either a specialist ADHD or adult mental health service. In contrast, we found that a joint planning meeting, a care plan and a joint handover period were conducted in fewer than 30% of cases. Other studies have also highlighted the lack of planning for transition of young people with ADHD (3, 4, 21, 22). Whilst the reported high level of involvement of the young person and carer in the process is commendable, paediatricians in particular reported poor continuity and consistency of care. This may reflect weaker links between paediatricians and adult mental health services when compared with CAMHS. A lack of planning is likely to undermine the potential for successful transition, and the need to adhere to recommendations to ensure effective transition has been highlighted (23). Further, it is recommended that policies and guidelines are reviewed regularly so they can be operationalised and effectively translated in to clinical practice (24). A systematic review of guidelines has suggested that this does not occur; guidelines are often not incorporated in to protocols locally and do not always reflect the clinical reality (25).

The use of the BPSU and CAPSS systems provided national level, prospectively collected data, but presented a number of methodological challenges. Registration to receive the monthly reporting cards is voluntary and mostly consists of those in the consultant grade. Therefore not all relevant clinicians may receive them (although doctors from non-consultant grades and non-medical staff may report cases via the consultant). This is likely to be the main explanation for the discrepancy between CAPSS and the CRIS case note review (11). Other research has demonstrated that patients may be reviewed in settings other than paediatrics and CAMHS such as primary care or forensic services (26) who would not ordinarily be reached by either surveillance system. There is also a relative underrepresentation of clinicians reporting to the surveillance units in the private sector despite its increasingly important role in health care provision (27), which may be particularly an issue for young adults with ADHD for whom there are few NHS services (7). Indeed, our findings highlighted referral back to primary care in

10% of cases. Incomplete data also presented a limitation; some contact details provided by both surveillance organisations were not up to date, and some questionnaires were returned blank or with missing data.

Whilst the return rate of reporting cards by paediatricians via BPSU was excellent, perhaps due to longevity of the system (28), the average return rate was much lower in CAPSS. CAPSS was set up more recently (2009), so is perhaps less ingrained in clinical practice for Child and Adolescent Psychiatrists than BPSU is for Paediatricians. The lower return rate may reflect a lack of awareness of the system and not necessarily a reflection of clinicians actively being non-compliant. Potential difficulties with the case definition could also have led to a lack of reported cases. Previous surveillance studies have also cited difficulties with reporting, case definitions and low return rates (29-32). Research is enshrined in the NHS constitution as a core activity (33), however clinicians reported that current workloads made it difficult to respond to questionnaires, and some service providers did not support their clinicians to participate. We provided certificates for questionnaire completion that indicated involvement in research for appraisals, but it is clear that busy clinicians need more support and encouragement to engage with research.

Surveillance methodology has stringent governance and required considerable researcher time for data collection and analysis, but has offered a more complete national picture of the need and success of transition to adult service among young people with ADHD than previous studies have achieved. Surveillance allows researchers to ask a wider and more tailored set of questions than case note review alone. The findings emphasise a relative lack of adherence to recommended guidelines for transition, and the low proportion of eligible patients that experience successful transition and a continuity of care.

Attempts have been made to correct for incomplete ascertainment and to provide a series of transparent estimates for policy, commissioning and service provision. Despite some limitations, to our knowledge these data are the best currently available. European studies have similarly highlighted

a lack of transition policy (15) and the societal impact of ADHD if not managed (20). Our findings are significant for commissioners and service providers, internationally as well as in the British Isles, to address the drop in attendance from child to adult services. It is imperative that mental health services develop policy and strategy to better support this group of young people in the future.

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Author Contribution: HE led the CATCh-uS surveillance study and the collation and analysis of data with support from AP. The study was designed by TF and AJ in collaboration with CA, TND, MP, KS and SY. RL facilitated data collection via BPSU and CAPSS. All other authors contributed to writing the paper.

Data Availability: Data is currently stored securely by the University of Exeter Medical School, under embargo until the end of the CATCh-uS project (2019).

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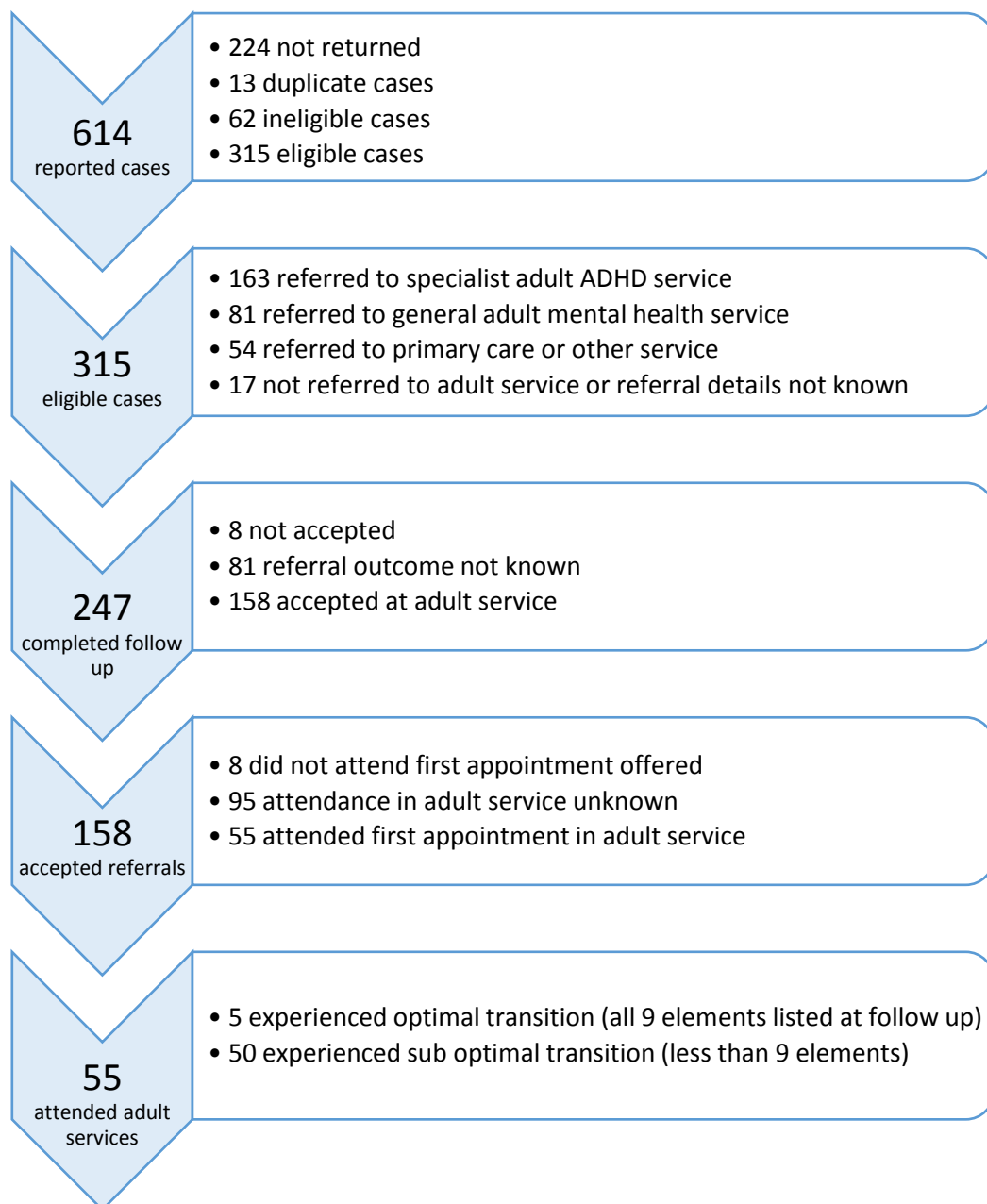


Figure 1. Reported cases, referral details, and optimal transition outcome.

Table 1. Surveillance study data November 2015-November 2016

Baseline (% based on total reported cases)	BPSU n=314	CAPSS n=300	Combined n=614
Not returned - received clear explanation for why	29 (9%)	27 (9%)	56 (9%)
Not returned - no explanation	41 (13%)	127 (42%)	168 (27%)
Duplicate cases	6 (2%)	7 (2%)	13 (2%)
Returned baseline questionnaire	238 (76%)	139 (46%)	377 (61%)
Ineligible cases	36 (11%)	26 (9%)	62 (10%)
Eligible cases	202 (64%)	113 (38%)	315 (51%)
Follow Up (% based on total eligible cases)	BPSU n=202	CAPSS n=113	Combined n=315
Returned follow up questionnaire	161 (80%)	86 (76%)	247 (78%)
Not returned - received clear explanation for why	12 (6%)	8 (7%)	20 (6%)
Not returned - no explanation	29 (14%)	19 (17%)	48 (15%)

Table 2. Calculation of observed and adjusted incidence rate of successful transition for cases aged 17-19 years (per 100,000 people aged 17-19 per year)

Observed incidence:	
Incidence: eligible for transition (all eligible cases identified in 12 months) per 100,000 per year	$(315 / 116,651) \times 100,000 = 270.0$
Incidence: successful transition (referral made, accepted and first appointment attended) per 100,000 per year	$(55 / 116,651) \times 100,000 = 47.1$
Incidence: eligible for transition aged 17-19 (all eligible cases aged 17-19 identified in 12 months) per 100,000 per year	$(269 / 116,651) \times 100,000 = 230.6$
Incidence: successful transition aged 17-19 (referral made, accepted and first appointment attended) per 100,000 per year	$(51 / 116,651) \times 100,000 = 43.7$
Correction for non-returned notification cards (no age known):	
Returned	73.7%
No response	26.3%
Assumption 1 (observed incidence applies to half (13.2) of non-returned (26.3%) cards because clinicians are more likely to respond with cases to report)	$(13.2 + 26.3) / 73.7 = \text{coefficient } 0.54$
Assumption 2 (observed incidence applies to all non-returned cards; assumes no difference in incidence between cases that were reported and not reported)	$100 / 73.7 = 1.36$
Correction for non-returned baseline questionnaires (no age known):	
Returned	$377 / 614 = 61.4\%$ $100 / 61.4 = \text{coefficient } 1.63$
Combined Coefficients for cases aged 17-19 only:	
Adjusted Incidence Rate 1 = incidence rate X Correction for unreturned notification cards (Assumption 1) X Correction for unreturned baseline questionnaires	Eligible for transition: $230.6 \times 0.54 \times 1.63 = \mathbf{202.9}$ Successful Transition: $43.7 \times 0.54 \times 1.63 = \mathbf{38.5}$
Adjusted Incidence Rate 2 = incidence rate X Correction for unreturned notification cards (Assumption 2) X Correction for unreturned baseline questionnaires	Eligible for transition: $230.6 \times 1.36 \times 1.63 = \mathbf{511.2}$ Successful Transition: $43.7 \times 1.36 \times 1.63 = \mathbf{96.9}$

Table 3. Factors of optimal transition reported – pre and post transition

PRE TRANSITION	BPSU n=202		CAPSS n=113		Combined n=315	
	Total 'Yes' response	%	Total 'Yes' response	%	Total 'Yes' response	%
Information sharing	176	87.1	93	82.3	269	84.6
Young person involvement	162	80.2	97	85.8	259	81.4
Planning meeting	23	11.4	29	25.7	52	16.3
Plan & agree care plan	49	24.3	46	40.7	95	29.9
Handover period	56	27.7	25	22.1	81	25.5
POST TRANSITION	BPSU n=161		CAPSS n=86		Combined n=247	
	Total 'Yes' response	%	Total 'Yes' response	%	Total 'Yes' response	%
User/carer involvement	116	72	56	65.1	172	69.6
Information sharing	105	65.2	65	75.6	170	68.8
Care plan agreed	35	21.7	44	51.2	79	32.0
Joint working before transfer	12	7.5	14	16.3	26	10.5
Alignment of assessment procedures	9	5.6	12	14.1	21	8.5
Continuity of care	35	21.7	41	47.7	76	30.8
Consistency of care	13	8.1	36	41.9	49	19.8
Consideration of appropriate service	78	48.4	50	58.1	128	51.8
Clarity of funding & eligibility	66	41.1	51	59.3	117	47.4